In the course of using this book, you may find yourself in need of some expert advice, or at least some additional information. This chapter steers you to resources available online or in the library and offers some tips on working with professionals.

TIP

The Internet is a great resource. Getting answers can be as simple as using a search engine to look up "special needs trust" or other words that describe your questions, such as "Illinois pooled trust," or "SSI eligibility standards." You'll quickly get a lot of hits. Be patient and discerning and you likely will find what you need.

Robert Berring, a well-known law professor, always advises that the first step in all research is: Talk to a human being who knows something about the subject. The humans you will want to talk to about your special needs trust are:

- lawyers who specialize in special needs planning law, elder law, or Medicaid issues and who can give you individualized advice, and
- financial planners with a background in assisting persons with disabilities, who can help you figure out how much property you'll need to put in the trust and how to set up a sensible budget.

Lawyers

You can't beat a knowledgeable lawyer for good legal advice. In fact, licensed lawyers are the only people permitted to give legal advice. Other professionals, such as financial planners, insurance agents, Social Security Administration (SSA) personnel, and paralegals, may incidentally dole out information related to special needs trusts as part of their overall services. Lawyers, however, are the only people you can go to for legal advice tailored to your individual situation.

When to See a Lawyer

First and foremost, you'll want to talk to a lawyer if you feel uncomfortable about doing this important task yourself.

Even if you are comfortable with drafting your own trust, it's important to keep in mind that special needs trusts are intended to last for many years. Questions may arise that weren't anticipated in this book, perhaps occasioned by big changes in the SSI and Medicaid rules. Having a relationship with a lawyer whose job it is to keep track of new legislation might save you and your loved one with special needs a lot of grief due to loss of public benefits and potential fines down the line.

Finally, this book tries to cover the situations that most people encounter, but it doesn't contain details that might be important to you if your situation is unusual. For example, if two of your children have disabilities and you want to provide for them in a single special needs trust, you'll need help beyond this book. On the other hand, if you create a separate trust for each child, then there is no problem. The point is, if you have questions that aren't answered between these covers, a lawyer can help.

Asking a Lawyer to Review a Trust You've Drafted

If you want to draft your own special needs trust but just need some additional information, ideally you should be able to have a short consultation with a special needs trust lawyer, pay a reasonable fee, and get all your questions answered. Even better, for an additional fee, the lawyer would review your trust, make helpful suggestions, and give you the peace of mind that comes from having a knowledgeable professional looking over your shoulder. Unfortunately, these scenarios are unlikely for two reasons:

- Many special needs trust lawyers think people shouldn't create special needs trusts themselves because of the complexity and ever-changing rules and regulations on public benefits.

- Lawyers may be concerned that if they give you piecemeal advice or services, and down the road something goes wrong that had nothing to do with the lawyer's review, you or your heirs will still sue for malpractice.

Additionally, most states' laws specify that when lawyers have reviewed one part of a document, this creates responsibility for the entire document. If something is wrong with a part of the document that the lawyer did not review, the attorney can still be sued for malpractice.

It's also difficult for lawyers to analyze someone else's trust document —even one created by another lawyer. They much prefer to simply use the one with which they are familiar.

This being said, an experienced special needs lawyer might be willing to go over the trust document from this book and give you advice.

For experienced special needs planning attorneys, the trust in this book should not be too difficult to review and give you advice on. In searching for a lawyer who will do this work, we recommend that you find one who has experience in drafting special needs trusts (not all estate planning attorneys will have that experience) and, if a lawyer agrees to provide this advice, that the fees for doing so are put in writing.

How to Find Special Needs Trust Lawyers

The world is full of lawyers—but finding one who has the expertise you need and a manner you like can take some shopping around.

General Estate Planning Lawyers

If you are already working with an estate planning lawyer—perhaps for your will or revocable living trust—that lawyer will most likely be able to help you or refer you to a special needs trust specialist. Be careful though—many estate planning lawyers will try and draft these trusts themselves even if they don't have the necessary experience. Use this book to educate yourself so that you can ask questions to see if your lawyer has the expertise to understand how to plan for your loved one with special needs.

Special Needs Planning Attorneys

The best way to find an attorney who specializes in this area is to go to the website for the Academy of Special Needs Planners. This is a national organization of attorneys devoted to doing planning for persons with disabilities. The organization has attorneys in just about every state with multiple attorneys in most states. You can search for an attorney in your state by going to www.specialneedsanswers.com/professionals.

You might also try to get a recommendation from someone in your own informal network of friends and acquaintances. You undoubtedly know people with a family member who has the same or similar disability as your loved one—they may have already found a lawyer who could help you.

You can also check in with any local or national group that concerns itself with a particular disabled population. There are hundreds of groups that focus on specific disabilities, such as spina bifida, paraplegia, cystic fibrosis, and autism. Chances are these groups work with lawyers who are adept at special needs trusts. Often, these lawyers have a child or relative of their own with a disability and have both practical and legal insights to offer.

Organizations that create pooled trusts (discussed in Chapter 6) can be an excellent place to obtain a referral. Go to the website of the Academy of Special Needs Planners at http://specialneedsanswers.com/pooled-trust to get contact information for pooled trusts in your state.

RESOURCE

When you're looking to hire a lawyer, try these excellent and free resources:

- **Nolo's Lawyer Directory.** Nolo has an easy-to-use online directory of lawyers, organized by location and area of expertise. You can find the directory and its comprehensive profiles at www.nolo.com/lawyers.
- **Lawyers.com.** At Lawyers.com you'll find a user-friendly search tool that allows you to tailor results by area of law and geography. You can also search for attorneys by name. Attorney profiles prominently display contact information, list topics of expertise, and show ratings—by both clients and other legal professionals.

- **Martindale.com.** Martindale.com offers an advanced search option that allows you to sort not only by practice area and location, but also by criteria like law school. Whether you look for lawyers by name or expertise, you'll find listings with detailed background information, peer and client ratings, and even profile visibility.

What to Look for in a Lawyer

First and foremost, you want a lawyer who has experience in drafting special needs trusts and to whom you feel comfortable asking questions.

In many parts of the country, you may have little choice of special needs trust lawyers. If so, as the old song goes, "Love the one you're with." But if you have several lawyers to pick from, here are a few questions to consider after an initial meeting:

- Does the lawyer seem interested in helping you resolve your specific questions and issues?
- Is the lawyer respectful of your self-help efforts?
- Does the lawyer seem confident of having the skills and knowledge to do the job well?
- Does the lawyer understand the disability and state benefits that your loved one with special needs is receiving?
- Are you willing and able to pay the lawyer's fee?
- Does the lawyer carry professional liability insurance?
- Perhaps most important, is the chemistry right? Do you feel reassured that you'll get exactly the services you need, no more and no less?

Paralegals

Social Security regulations explicitly authorize nonlawyer paralegals to represent clients in administrative proceedings dealing with benefit disputes. So if you have questions about your state's SSI and Medicaid income and resource rules, a paralegal may be a good resource.

You can find paralegals in your area by searching online or using the yellow pages. In your area they might be called "document preparers" or "legal document assistants." Look for a paralegal who specializes in SSI and Medicaid matters, and compare fees.

Paralegals who work in the Social Security area are largely unregulated. If you want recourse in case you get bum advice, hire a paralegal who carries "errors and omissions" insurance—many do. Of course you may have to pay more if your paralegal is insured, but it may well be worth it.

If you need information about customizing your special needs trust or your options for a different type of trust—for instance, one that takes effect at your death—you'll need to see a lawyer. Paralegals are limited to advice and information about Social Security matters. While paralegals are often critical team members in special needs planning law firms, they are prohibited from giving legal advice.

Certified Financial Planners

Special needs trusts may involve financial planning over a long period of time. Financial planners are people with accounting, investment, and insurance knowledge who can help you compute how much money you will need to accomplish your general estate planning goals and adequately fund your special needs trust.

Financial planners are not licensed professionals, but a central board certifies them. (For information about the certification process, visit www.cfp.net.)

Financial planners can provide a wealth of information on:

- how much money the special needs trust will need to accomplish your goals for your loved one
- a budget for the trustee who will manage the trust, and
- the best sources of funding for the trust, including advice on insurance options.

Just like attorneys, not all financial planners understand the unique financial requirements of a person with special needs. Make sure that the financial planner you select understands the financial needs that your loved one will have. Be sure to ask all of them how many times they have planned for a person with a disability and how they will incorporate public benefits into their planning. If they cannot answer these questions to your satisfaction, find another planner.

To find a local certified financial planner, visit these websites (or enter "certified financial planner" and your city's name into your favorite search engine):

- www.fpanet.org
- www.paladinregistry.com, or
- www.wiseradvisor.com.

Also some large financial institutions have planners who specialize in this area of financial planning:

- MassMutual has a program called Special*Care*, dedicated to special needs financial planning. The program provides information, specialists, and financial solutions to families with dependents of any age who have a disability. To get started, visit the company's website, www.massmutual.com/specialneeds.
- Merrill Lynch & Co. has set up a program that focuses on financial planning for special needs families and has a training program for its brokers. Call 877-456-7526 or visit the company's website at www.ml.com.

CAUTION

Financial planners aren't always disinterested advisers. Many financial planners are affiliated with one or more insurance companies. Their advice may be sound, but they also have interest in selling insurance at rates that might not be in your best interest. Especially when you are exploring insurance options, make sure you ask the right questions. See Chapter 4.

SSA and Medicaid Personnel

A special needs trust is designed to preserve your loved one's SSI and Medicaid benefits. If you need more information about those benefits than this book provides, ask someone at your local SSA office. You may get lucky and get your question answered. However, even SSA and Medicaid personnel don't always know the rules, so be sure to get a second opinion before following their advice.

If a program near where you live delivers legal services to the poor, you might visit it and see what materials it has. You might find written resources explaining various aspects of the SSI and Medicaid programs, and the staff may be able to answer your questions.

Keeping Up to Date

Many years may pass between the time you create the trust and the time when it is fully funded (probably at your death). For example, if you are in your 40s or 50s when you create a special needs trust, at least 30 or 40 years will probably go by before you die. During that time, things that may happen include:

- SSI and Medicaid rules change in ways that require you to revoke or amend the trust.
- SSI and Medicaid rules change and make your loved one ineligible for benefits—which would eliminate the need for a special needs trust.
- Your loved one develops additional needs that you want to specifically provide for in the trust.
- Your loved one is no longer disabled and can inherit the property outright.

Obviously, you need to stay on top of such developments.

Subscribe to the Authors' Monthly Online Newsletter

Authors Kevin Urbatsch and Michele Fuller-Urbatsch send out a monthly online newsletter called the "Special Needs News." The newsletter provides updates on public benefits and issues that involve persons with disabilities. To receive the newsletter, go to www.urblaw.com or www.michiganlawcenter.com and follow the instructions for signing up.

Disability Groups' Newsletters and Websites

One excellent way to keep up to date on changes is to become active with a group that cares about disabilities and check its newsletters and website. Such an organization will pick up on any changes in government regulations. Some groups are listed below. You can also get information from groups that focus on a specific condition, such as autism or Down syndrome.

Getting Information About Disability Benefits and Laws

- Academy of Special Needs Planners, www.specialneedsplanners.com
- *Exceptional Parent* magazine, www.eparent.com
- Federal government agencies that provide services to persons with disabilities, www.disability.gov
- National Alliance on Mental Illness (NAMI), www.nami.org, and
- The Arc, www.thearc.org.

Federal Statutes and Regulations

If you want to be connected directly to the source of SSI and Medicaid regulation changes, you can read the government regulations themselves. Some of the language is dense, but the regulations can be helpful if you

are willing to take some time to read and digest them. Most of them are in Volume 20 of the Code of Federal Regulations (C.F.R.), Section 416. Online sources are listed below.

Topic of Regulation or Statute	Citation	Website
Regulations issued by the Social Security Administration	20 C.F.R. §§ 416.101–416.2227	www.gpo.gov/fdsys
SSI resource rules	20 C.F.R. §§ 416.1210–416.1238	www.gpo.gov/fdsys
SSI in general	20 C.F.R. §§ 416.101–416.2227	www.gpo.gov/fdsys
Medicaid	42 C.F.R. §§ 430–456.657	www.gpo.gov/fdsys
Medicaid eligibility	42 C.F.R. §§ 435.700–435.740	www.gpo.gov/fdsys
Guidelines relied on by workers at the Social Security and local district offices	POMS (*Program Operations Manual System*)	http://policy.ssa.gov
State rules for Medicaid		www.medicaid.gov
How local SSI and Medicaid offices must treat special needs trusts	42 U.S.C. § 1396r-5 (Medicare Catastrophic Coverage Act of 1998), 42 U.S.C. § 1396p(d)(4)(A–C)(a–e)	www.ssa.gov

The particular areas of interest to you at all these sites are:

- how the SSI and Medicaid programs view special needs trusts funded by third parties
- what property the SSI and Medicaid programs consider the recipient's countable resources for eligibility purposes
- what the SSI and Medicaid programs consider to be income, and
- what the SSI and Medicaid programs consider to be income in-kind, including in-kind support and maintenance (ISM).

CAUTION

Help with legal research. Legal research, like other types of specialized research, has its own logic and terminology. Finding appropriate cases, knowing how to read them, and knowing how to find out whether a case you find is still good law are beyond the scope of this book. But Nolo can help you: *Legal Research: How to Find & Understand the Law*, by Stephen Elias and the Editors of Nolo (Nolo), will get you where you need to go.

Books

Needless to say, a fair number of books discuss persons with special needs. Most deal with raising children with special needs and address the entire subject, from cradle to grave. Special needs trusts are but one subject of many.

To find these books, simply go to a good bookstore and look in the special needs or parenting sections. Or try an online bookstore and search for "special needs." You may be surprised at how many titles appear.

A few books provide a more detailed discussion of special needs trusts, both self-settled and third-party trusts. Many of them were written for lawyers, and you're most likely to find them in a law library. Law libraries accessible to the general public typically are located in courthouses, civic center buildings, or public law schools.

All law libraries have reference librarians, who are generally most helpful and willing to get you started. Just ask for materials on special needs trusts and you'll probably be given more than you can comfortably deal with.

RESOURCE

Learn about administering a special needs trust. *Administering the California Special Needs Trust*, by Kevin Urbatsch and Michele Fuller (iUniverse), explains to trustees how to administer a special needs trust. You can find this book through Amazon.com or Barnes and Noble.